



Understanding the experience of living with non-small cell lung cancer (NSCLC): A qualitative study

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Background: As non-small cell lung cancer (NSCLC) treatments improve and patients live longer, it is increasingly important to develop interventions to help patients live fuller lives. We sought to identify key components of quality of life (QOL) and social support in determining therapeutic decision-making and overall value of life-extension, in patients with NSCLC.

Methods: Three semi-structured focus groups (n=16) and telephone interviews (n=15) were conducted and recorded with NSCLC patients (N=31), to explore the full range of symptoms that patients considered important to QOL. A tradeoff format assessed the value of life-extension relative to QOL. Patients were asked to consider a hypothetical treatment option that offered on average a 3 month life extension.

Results: Mean age was 61.6 years, 67.6% were female, 77.4% white, 61.3% were not employed/retired, 58.1% were living with a spouse/other, 93.5% had health insurance, and 48.4% were Stage III/IV. Sixty-Eight percent of patients conceptualized emotions and attitudinal orientation as **symptoms** of NSCLC. Key symptoms/concerns changed over time – 74% of patients reported shock and fear at diagnosis, 55% felt fear or loneliness during the beginning of therapy, 52% successfully connected with other NSCLC patients (peers) and support groups, and reported a positive shift in feelings with social/emotional support from all social networks. 26% of patients reported confusion and isolation during treatment due to education gaps. Financially, 23% of patients reported being adversely impacted by co-pays, 36% by unexpected gaps in coverage, 39% by other bills, and 52% accepted help from any/all sources. The most important factor driving treatment-decision making about life-extending therapy was the somatic (i.e., physical symptom) dimension (84% cited as important), followed by functional (32%), relational (23%), and emotional (10%) factors.

Conclusions: Patients with advanced NSCLC tend to conflate emotional well-being post diagnosis with symptoms of their cancer and treatment toxicities. However, somatic QOL concerns, ahead of functional, emotional and relational QOL, emerge as the dominant driver of therapeutic decision-making.